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In The

SUPREME COURT OF THE UNITED STATES

October Term, 1980

Nos. 70-1404, 79-1408, 79-1414, 79-1415, and 79-1489

Pennhurst State School and Hospital, *et al*,

Petitioners,

v.

Terri Lee Halderman, *et al*,

Respondents.

On *Writ of Certiorari* to the United States Court of Appeals for the Third Circuit

Motion for leave to file brief *amici curiae* and brief for **People First International, Inc., People First of California, Inc., Mohawks and Squaws, America Coalition of Citizens with Disabilities, Inc., Center for Independent Living, Inc., Prime Movers, Inc., Center for Independence of the Disabled of New York, Inc., Washington Coalition of Citizens with Disabilities, Community Service Center for the Disabled, Inc., Holistic Approaches to Independent Living, Inc., Access Living of Metropolitan Chicago, Illinois Council, Congress of Organizations of the Physically Handicapped, Paraquad, Inc., Stavros Foundation, Coalition for Barrier Free Living, Inc., as *amici curiae***

Of Counsel:

STEVEN M. FLEISHER
Fleisher & Neckritz
1440 Broadway, Suite 702
Oakland, CA 94612
(415) 763-9670

ROBERT J. FUNK

DEBORAH KAPLAN
Disability Rights Education
Defense Fund
Center for Independent Living
2539 Telegraph Ave.
Berkeley, Ca. 94704
(415) 548-4274

Attorneys for Amici Curiae

October 16, 1980

Berkeley, CA **CALGRAPHICS** (415) 548-8492

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MOTION FOR LEAVE TO FILE BRIEF
AMICI CURIAE

People First International, Inc, (hereinafter referred to as "People First") and the organizations named in paragraph 1 hereof, move for leave to file the attached brief amici curiae.[1]

1. People First International, Inc. , People First of California, Inc. & the Mohawks & Squaws are organizations of persons who are retarded. Their interest in this case, as well as all amici, is fully explained in the "Interest of Amici" section of the attached brief. As representatives of the class of persons that will be most affected by this case, People First International and other organizations of persons who are retarded support the decisions below and the principle that all persons, regardless of their degree of disability, have the right to receive services designed to enhance, rather than retard, their capabilities.

2. The American Coalition of Citizens with Disabilities, (ACCD) as an umbrella organization representing persons of all disabilities throughout the nation, was founded on the principle that all persons with disabilities should be able to control their own lives, to the maximum extent possible, and to live in an integrated setting in their communities.

[1] All respondents have consented to the filing of this brief, and the United States has indicated that it expects to consent. Petitioners have not yet indicated whether they will consent.

3. The Center for Independent Living and other independent living centers are community-based organizations, directed and staffed by persons with disabilities. Their primary objectives are to provide services for persons with severe disabilities to enable them to live within the community, and to advocate for the rights of persons with disabilities. Because of the availability of the services from amici and other independent living centers, substantial numbers of persons with disabilities have been able to successfully move into their communities and avoid institutionalization.

4. Congress has repeatedly expressed recognition of the competence of persons with the most severe disabilities to learn and enhance their abilities, when provided with services tailored to their particular needs in the community. Congress has specifically rejected the medical model that regards persons with severe disabilities as diseased. It has accepted the developmental model, which regards severely disabled persons as individuals, capable of continual improvement.

5. Congress has also recognized that persons with disabilities are entitled to take part in decision-making processes involving their lives and to speak for themselves, to the maximum extent possible. People First International, et al., as organizations directly representing those who will be affected by the outcome of this case, believe that their experiences and views deserve to be heard. As Amici's brief demonstrates, the Court below based its opinion on clearly expressed mandates from Congress.

CONCLUSION

Amici have a substantial and direct interest in this case; they have a unique and important perspective concerning the issues before this Court. Therefore, this motion for leave to file a brief as amici curiae should be granted.

Respectfully submitted,

Steven M. Fleisher
Fleisher & Neckritz
1440 Broadway, Suite 702
Oakland, California 94612
(415) 763-9670

Robert Funk
Deborah Kaplan
Disability Rights Education
Defense Fund
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 548-4274

For Amici

BRIEF FOR PEOPLE FIRST INTERNATIONAL, INC., et al., AMICI CURIAE

INTEREST OF THE AMICI

Amici represent three different categories of groups representing people with disabilities: People First International and other organizations of persons with retardation, the American Coalition of Citizens with Disabilities, and Independent Living Centers.

PEOPLE FIRST INTERNATIONAL AND OTHER ORGANIZATIONS OF PERSONS WITH RETARDATION

People first International Inc., was formed in 1974 and is a non-profit corporation under the laws of the state of Oregon. People First International was organized by persons who are retarded in Salem, Oregon, who felt the need for their own community support network, and it was the first organization of persons with retardation in the country.[1] People First International provides peer support services for people who are retarded and are moving from institutions into the community, and those who have resided in the community for an extended period of time. Based on the principle that persons with retardation can and should speak for themselves, People First International provides members with assistance in communicating with others, understanding social service program requirements and rules, and organizing members to advocate for transportation, housing and employment.

People First International is a full partner organization in the U.S. Council for the International Year of Disabled People. People First

[1]From MR:78, Report to the President, President's Committee on Mental Retardation: The Leading Edge, Programs that Work", p. 53:

> A gentle protest can now be heard throughout the nation from mentally retarded persons who are tired of being over-protected. They

International members are on the Boards of Directors of the National Association for Retarded Citizens, the Oregon Association for Retarded Citizens, the Oregon Developmental Disabilities Advocacy Center, the State Developmental Disabilities Council and the Governor's Committee for the Handicapped. People First International members have testified at a variety of local and state legislative bodies concerning programs, funding, zoning budget cuts, guardianship and conservatorship legislation, sterilization legislation and other issues. People First International has received requests from all 50 states and eleven foreign countries, for information.

People First of California, Inc., is a non-profit corporation incorporated under the laws of the State of California. The by-laws of People First of California state:

> Article II, Section 2: The specific and primary purposes for which this corporation (is founded) shall be to offer adults with developmental disabilities the opportunity to reach their highest possible levels of self-determination by assisting them in: (a) supporting the right of people with developmental disabilities to

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have begun to object when professionals and non-professionals make decisions for them and speak for them, when, with a little time and patience, they could have decided and spoken for themselves. These first protests are, perhaps, the latest step in a natural evolution: They have come out of groups of handicapped persons in community settings where new styles of organization have enabled individuals to speak more genuinely about themselves than ever before. (from an article on People First.)

live independently.
(b) advocating for resources which are needed and not presently available. Resources include such things as money, work, education, housing, legal and social justice.
(c) supporting the right to provide some services for themselves which are now being provided by parents and professionals. These services may include counseling, citizenship, education, community organizing, and social/ recreational activities.
(d) educating their community, both professional and disabled, as to their goals, capabilities and responsibilities.

People First of California was founded in 1976, and its governing board and officers are comprised of members of the organization, people with mental retardation themselves.

The Mohawks and Squaws is a non-subsidized group of persons who are retarded in the area of Boston, Massachusetts. Organized as a peer support group and social club, the Mohawks and Squaws has provided consultation to colleges and professional schools, parent and client groups on issues related to the rights and needs of persons who are retarded. It has also provided training in the public schools to acquaint school children with concerns of disabled persons. It provides support to members who reside in state schools and wish to join the community; it has a teen-age group and a Sunday drop-in Center.

The above-described organizations representing persons with retardation have a direct interest in this case because their constitutents will be directly affected by the outcome. All of these organizations promote the right of persons who are retarded to speak for themselves and to live as

independently as possible within their communities. Based on their own experiences, their members strongly believe that all persons with retardation can expand their abilities when provided services tailored to the individual in a family-sized community setting.[2]

AMERICAN COALITION OF CITIZENS WITH DISABILITIES

The American Coalition of Citizens with Disabilities (hereinafter referred to as ACCD) is an umbrella group, consisting or organizations of disabled people. Founded in 1973, ACCD's active membership consists of 89 organizations representing approximately seven million people. ACCD's member organizations include the National Association of the Deaf, the American Council of the Blind, the National Spinal Cord Injury Foundation, and others. ACCD's Board of Directors consists of persons with disabilities; its primary goal is to represent disabled people's interests and to join together the various voices and views of disabled people across the country to speak with one voice.

ACCD has been a major participant before the Congress in the formulation of policies and legislation concerning disabled people's needs and rights.[3]

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[2] Appendix A, attached to this brief, lists selected individuals represented by amici to further illustrate their membership.

[3] Review of Programs for the Handicapped, 1977: Hearings before the Senate Subcommittee on the Handicapped ofthe Comm. on Human Resources, 95th Cong., 1st Sess., 1325 (statement of Jan Jacobi, ACCD.) Education for All Handicapped Children Act, 1977: Hearings before the Senate Subcommittee on the Handicapped of the Comm. on Human Resources, 95th Cong., 1st Sess. 132 (statement of Frank Bowe, ACCD).

ACCD regularly conducts training sessions and prepares written materials on such subjects as: consumer involvement in the rehabilitation process, enforcement of the civil rights of disabled people, educational opportunities and rights of disabled children and adults, and independent living for severely disabled persons.

ACCD has an interest in this case because it represents organizations and coalitions of disabled people, including people who are retarded and multiply handicapped, from the national to the local level. Many of the people that ACCD represents have at one time been or still are living in institutions. ACCD conducts several activities designed to increase the alternatives available to allow people with severe disabilities to live in their communities. Presently it is representing individuals who are residents of Forest Haven, a residential institution for the District of Columbia located in Maryland, subject to a court order requiring placement. (Joy Evans v. Walter Washington, et al., C.A. #76-0293, (Dist. Ct. D.C.), June 14, 1978.)

INDEPENDENT LIVING CENTERS

The Center for Independent Living (hereinafter referred to as C.I.L.) is a non-profit corporation organized under the laws of the State of California. Founded in 1972, the major goal of C.I.L. is to provide support services and advocacy for persons with severe disabilities who would not be able to live independently in the community without such services and advocacy.[4] The C.I.L. Board of Directors consists of a majority of people with disabilities themselves; this philosophy and

[4]As the first independent living center in the country, C.I.L. has served as a national model for other such organizations across the country. In 1978, the Subcommittee on Select Education of the U.S. House of Representatives held 2 days of

commitment to control of the organization by disabled people is further evidenced by the high proportion of severely disabled persons who are administrators and staff at C.I.L.

In order to fulfill its goals, C.I.L. provides the following services to disabled people in its community: attendant care referral, housing referral, wheelchair repair, peer counseling, welfare advocacy, legal services, independent living skills training, and others.

Prime Movers, Inc., was founded in 1977 and operates out of Louisville, Kentucky. Its primary goal is to eliminate environmental factors such as barriers to housing, transportation and facilities, as well as attitudinal barriers which separate disabled people from their community.

Prime Movers has provided consultation services tocommunity organizations such as the Kentucky Cultural Complex Committee, the University of Louisville Urban Studies Center and the Kentucky Legislative Research Commission, among others, for devising methods to integrate all disabled people into community programs and facilities. Its major current project is the Disabled Housing Options Center, which will work to provide a range of integrated housing options for disabled persons.

The Center for Independence of the Disabled in New York, Inc., (hereinafter referred to as CIDNY) is a non-profit corporation organized under the laws of New York State in 1977. It is managed and directed by persons with disabilities.

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hearings at C.I.L. to receive testimony on the subject of implementing this model on a national level, which was accomplished in Title VII of the Rehabilitation Act Amendments of 1978, 29 U.S.C. §901 et seq., discussed infra at p.18. Oversight Hearings on the Rehabilitation Act of 1973: Hearings before the Subcommittee on Select Education and Labor, 95th Cong., 2nd Sess.

CIDNY's major goal is to provide services to allow severely disabled persons to live independently.

As a resource center for the disabled community, CIDNY provides: assistance with household management, independent living counseling, housing information, information on benefits and social service programs, peer counseling, vocational rehabilitation information, legal referral services, transportation information, and advocacy.

Access to Independence, Inc., is a non-profit corporation formed under the laws of the state of Wisconsin. Located in Madison, Wisconsin, its Board of Directors includes fifteen members, eight of whom are severely disabled.

Since 1978, Acess to Independence has been providing a range of supportive services to disabled persons: housing counseling and technical assistance; attendant recruitment, referral and counseling; information and referral services; a free university program to increase knowledge about independent living skills; a sheltered apartment program; peer counseling services; and within the Center, an on-the-job apprenticeship program.

The Washington Coalition of Citizens with Disabilities (hereinafter referred to as WCCD) was organized in 1977 as an umbrella of the following groups in Washington State: Arthritics in Action, Congress of the Physically Handicapped, Disabled in Action of Washington, Disabled Students Commission at the University of Washington, Puget Sound Chapter of the National Rehabilitation Association, Northwest Paralyzed Veterans of America, Polio Alums, Washington Association of the Deaf, and the King County Chapter of the Washington Council of the Blind.

WCCD provides services to Washington State disabled persons that include attendant referral,

peer counseling, and advocacy. WCCD has provided technical assistance on provision of services to include disabled persons to public agencies concerned with transportation, employment, housing, civil rights, chore services, in-home care entitlements, and health. WCCD's Board of Directors is composed entirely of disabled persons, and it is staffed primarily by disabled persons.

The Community Service Center for the Disabled, Inc., (hereinafter referred to as CSCD) is a consumer-controlled social and community service agency providing independent living services to more than 1,300 disabled persons a month in San Diego, California. Incorporated as a non-profit organization under the laws of the state of California in 1976, CSCD is San Diego's central clearinghouse for services and community education in issues relating to the positive movement of disabled people into the economic, social, personal and political mainstream. CSCD provides advocacy, personal helper referral, housing and transportation services to disabled San Diegans. It also provides peer counseling and job development services.

The Illinois Council of the Congress of the Physically Handicapped (hereinafter referred to as COPH) is a congress of 32 organizations of persons with physical disabilities and individual members, representing a constituency of five thousand members in the state of Illinois.

For the past fifteen years, COPH's activities and projects have provided information, referral, peer counseling and advocacy for persons with disabilities to help them gain full participation in society.

Access Living of Metropolitan Chicago is a consumer-operated service and advocacy organization that serves disabled persons in the Chicago area. It is affiliated with the Rehabilitation

Institute of Chicago. Based on the philosophy that disability does not have to mean dependency, Access Living's services include: housing referral, personal care assistant training and referral, educational programs for independent living, peer counseling, financial benefits counseling, independent living skills counseling, information referral and advocacy.

Paraquad, Inc., is a non-profit corporation organized in 1970 under the laws of Missouri to develop integrated living for the physically disabled in an accessible environment. Paraquad provides the St. Louis' disabled community with assistance in housing, barrier-free design, independent living counseling, peer counseling, consumer advocacy, and community relations.

Paraquad's Board of Directors is predominantly composed of persons with disabilities, reflected as well in Paraquad's staff composition.

The Stavros Foundation, Inc., was founded as a non-profit corporation under the laws of Massachusetts in 1974. It is a consumer-controlled independent living center with disabled persons forming a majority of its Board of Directors and staff.

Stavros provides peer advocacy counseling, individual and group advocacy, information and referral, and general consulting in independent living. It serves the Amherst, Massachusetts, area, in addition to the counties of Franklin, Hampshire, and Hamden.

Holistic Approaches to Independent Living, Inc., is a Denver-based non-profit corporation formed in 1978 under the laws of Colorado. It is organized and operated by persons with disabilities and provides attendant care referral and counseling in advocacy, housing, employment and recreation, as well as classes in independent living.

The Coalition for Barrier Free Living is a non-profit organization, formed in 1976 under the laws of the state of Texas. Its Board of Directors and staff are both composed predominantly of persons with disabilities. It provides the following services to persons with disabilities in Houston, Texas: service for deaf persons and blind persons, information and referral, financial benefits counseling, attendant referral, independent living skills training, training for developmentally disabled persons, and job development.

This case is of great interest to the Independent Living Center Amici because of the dual nature of their experiences as organizations composed of and representing persons with disabilities, on the one hand, and as providers of services to severely disabled people, on the other. Many of the people they serve would otherwise be forced to reside in nursing homes or institutions because there are so few alternatives available for community living.[5]

The experiences of Amici are that the social segregation and isolation associated with institutions are unnecessary and destructive to the individual, regardless of the severity or nature of the disability. A corollary experience of Amici is that the very nature of placement in an institution brings out those negative and dependent qualities in those who reside there; they are less able to speak for themselves, make decisions, or exert any other means of control over their lives.

Amici, as organizations representing and controlled by persons with disabilities, intend to rebut in this brief those assertions made by petitioners and Amici arguing for petitioners that disabled people, especially severely disabled people, are without the capability to speak for themselves

5. See, "National Significance Project: Programs and Resources", United Cerebral Palsy Association of California, February 1978, p. 15.

or make meaningful decisions about their lives. Such assertions are based on out-dated notions about people with severe disabilities.

Amici represent individuals with disabilities who would have been institutionalized decades ago. We now know that people with cerebral palsy, epilepsy, who are blind, deaf or mobility-impaired can function better in the community than ever expected; yet, when people with these disabilities were institutionalized for most of their lives, they displayed many characteristics that suggested they could not function or survive outside of the institution. As past victims of unnecessary institutionalization, Amici suggest that mental retardation is simply the last in a list of disabilities that used to be synonymous with "hopelessness."

As Amici will show, it has been recognized by Congress and is widely recognized by others that people with all disabilities function best when integrated into the community with appropriate services.

SUMMARY OF ARGUMENT

A central principle that emerges from a review of legislation concerning the rights of and services to persons with disabilities enacted during the previous decade is that persons with the most severe disabilities are capable of learning and growing, despite historical expectations to the contrary. Congressional committees have spent years researching this issue and receiving testimony from those directly involved and experts in the field. Congress brings to this issue "a specially informed legislative competence," Katzenbach v. Morgan, 384 U.S. 641, 655 (1966), which is due great consideration. The decision below is consistent with Congressional instructions that:

> all developmentally disabled individuals have potential for learning and growth. From this developmental model, it follows that custodial care--which is predicated on the assumption that certain individuals are essentially incapable of development--must be rejected... S. Rep. 94-160, 94th Cong., 1st Sess., at. 29 (1975).

The Congress has also recognized the need for disabled persons to speak for themselves and has acknowledged that they best represent their own interests. Amici believe that by advocating for themselves, they can rebut the commonly held assumption that they are not fully capable of doing so.

ARGUMENT

I. CONGRESS HAS REPEATEDLY RECOGNIZED THAT SEVERELY DISABLED PERSONS, INCLUDING THOSE WITH SEVERE AND PROFOUND RETARDATION, ARE CAPABLE OF GROWTH AND IMPROVEMENT.

Congress has dealt with the issues of protecting the rights of persons with disabilities and providing services to persons with disabilities many times. In doing so, it has made it amply clear that it rejects the view that the most severely disabled people, including persons with severe or profound retardation,[7] are not capable of progressing and improving their abilities to function, whatever their individual limitations. Even though Congress has definitively addressed this issue, it is repeatedly raised in the brief of Amici Congress of Advocates, et al., and is implicit in the dissenting opinion of the Third Circuit, written by Chief Judge Seitz, 612 F. 2d 84 at 125 (3d Cir. 1979).

In attempting to re-litigate by brief the factual issues that were disposed of by District Court Judge Broderick after 32 days of trial and disposed of previously by Congress as well, the Congress of Advocates paints a bleak and hopeless picture of the nature of severe and profound retardation, (Congress of Advocates brief, pp. 3-6). Citing materials suggesting that persons with profound retardation can barely function at all, referring to their status as "helplessness," and further stating that "the picture is not much

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[7] For the purpose of simplicity, Amici will use the term "severely disabled person" or "person with a severe disability" to refer to persons with severe or profound retardation and other severe disabilities.

brighter with respect to the 'severely' retarded...," the Congress of Advocates rely on frightening and out-dated stereotypes to make their argument.

The dissenting opinion of Chief Judge Seitz is based on the misconception that people with severe disabilities can only function at a very low level and that the type of care they receive does not affect their ability to function or improve. This leads the dissent to the conclusion that institutions need only meet certain minimal standards of cleanliness and staffing, without adressing the larger issues of the relationship between institutionalization and behavior.

This reasoning becomes apparent when the dissenting opinion is read for what it does not mention. Nowhere does it discuss the need for habilitation, training and the development of skills for less restrictive placement in the community. Several times the dissent lists the "necessities" that are provided at an institution: "food, shelter, medical care, and supervision," 612, F. 2d at 125. However, Congress and the District Court recognized that persons with severe disabilities are capable of more than receiving custodial care when they are provided appropriate training and habilitation, and the court correctly found that institutions cause residents to regress in those very skills and abilities needed to leave the institution. The Court also found that at Pennhurst there is no opportunity to practice newly learned skills; that the environment there was not conducive to habilitation; and that the restrictive, depressing routines of institutions such as Pennhurst actually contribute to the lack of ability to function that is commonly attributed to residents. 612 F 2d at 93.

Congress and the District Court could not ignore the effect of the institution on the behavior of individuals with severe disabilities

who have been housed in the institution for a large segment of their lives. Consistent with both the strong mandates of Congress on this issue, and with the experiences of Amici, the District Court found that retarded persons in large institutions suffer from "apathy, stunted growth and loss of IQ, and the smaller the living unit in which the retarded person lived, the higher the level of behavioral functioning shown by the individual." 612 F. 2d, at 93.

Amici represent individuals who do not need to read materials on the principles of normalization and integration to know their truth. They have lived in large-scale dehumanizing institutions, many of them with severe disabilities, and they have experienced firsthand the debilitating effects of such treatment. Because of the various enactments requiring community living arrangements rather than institutionalization, they have been able to move into their communities and function better than expected, in the majority of cases. They have not perished or been forced to return to the institution because they are incapable of avoiding "the hazards of freedom" which concerned Chief Judge Seitz. Because there are alternatives, they have been able to improve their abilities on a continual basis. Each person has no doubt that if they were forced to return to the institution, such improvement would diminish and stop.

The Congress has considered the experiences of Amici and others like them, as well as the available research and testimony of experts on the subject. The Senate Subcommittee on the Handicapped of the Human Resources Committee, which has jurisdiction over most of the legislation dealing with services to persons with disabilities and their rights, has spent several years hearing evidence and holding hearings on this subject. It has consistently produced legislation which recognizes the capabilities of severely disabled people, mandating that services be provided in

the community, structured to meet the needs of the individual.

A review of the record of the Subcommittee on the Handicapped and other committees that have acted in this area shows that Congress brings to this issue "a specially informed legislative competence," Katzenbach v. Morgan, 384 U.S. 641, 655 (1966), which this Court has held is the special prerogative of the legislative branch, having the power to assess and weigh various conflicting considerations of a complex issue. Based on this legislative competence, Congress has repeatedly acted to recognize the competence of severely disabled persons to live within their own communities and to grow and learn.

In the past decade, Congress has passed four major acts dealing with services to and the rights of people with disabilities: The Developmental Disabilities Assistance and Bill of Rights Act,[8] The Rehabilitation Act of 1973, as amended in 1974 and 1978,[9] the Education for All Handicapped Children Act,[10] and the White House Conference on Handicapped Individuals Act.[11] A review of these Acts and their legislative history reveals the following strong and interdependent themes: (1) Congressional recognition of the inherent strengths and capabilities of persons with severe disabilities (2) Recognition that such capabilities can best be fostered by the provision of services, education and training in the community, either in an independent living arrangement or in family-sized residential settings located in the general community for those in need of supervision and individualized assistance; (3) Requirements

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[8] 42 U.S.C. 600, et seq.

[9] 29 U.S.C. 701, et seq.

[10] 20 U.S.C. §§1232, 1401, 1405, 1406, 1411-20, 1453.

[11] 29 U.S.C. 701, Note (Dec. 7, 1974).

that such services be individually tailored to the disabled person's needs and abilities.

The legislative history of the Bill of Rights Act shows clearly that Congress recognized the capabilities of severely developmentally disabled persons to learn and grow. In discussing persons with multiple handicaps, the Senate Committee on Education and Labor declared, "A large percentage of all these citizens are so severely disabled as to require a lifetime array of services to reduce dependency or to develop potential abilities for personal and social functioning,"(emphasis added) S.Rep. 94-160, 94th Congress, 1st Sess., at 2(1975). Rather than relegating the most severely disabled to custodial care and institutions, Congress concluded that, from its own exhaustive research and several hearings, all disabled persons have the potential for growth.

Congress recognized that this growth must take place away from impersonal, institutionalized settings:

> Finally there is the view that developmentally disabled individuals are "diseased". They are viewed as sick and in need of constant care. This last model is gradually being replaced by a developmental view of mental retardation. Such a view stresses that all developmentally disabled individuals have potential for learning and growth. From this developmental model, it follows that custodial care - which is predicated on the assumption that certain individuals are essentially incapable of development - must be rejected...A final but critically important dimension of this new model is that developmentally disabled persons should live like non-developmentally (disabled) persons to the greatest degree possible. Every effort should be made to assist developmentally disabled persons to maximize their ability for self-care and to live normal lives. S.Rep.94-160 at 29.[12]

In the Rehabilitation Act of 1973, Congress required

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12. In the dissenting opinion, which would allow

that the state rehabilitation agencies, which receive their funding under that Act, reorder their priorities by serving first persons with "the most severe handicaps", 29 USC §701(a)(5)(A). The legislative history for this Act reveals a Congressional commitment to those whose disabilities were so severe that they had previously been denied rehabilitation services:

> However, the Committee, in changing the definition of handicapped individuals, also recognizes that there are handicapped individuals who may not have a vocational goal due to the severity of their handicap, their age, or other factors, but who can greatly benefit from rehabilitation services. While emphasizing that every effort should be expended to provide services to individuals so that they may reach a vocational goal, the Committee believes that individuals can benefit from services which will enable them to live more independently and to be more self-sufficient, and has directed the Secretary to study the feasibility of methods of accomplishing these goals. S.Rep.93-318 at 21,(1973) U.S. Code Congr. & Ad. News at 2095.[13]

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the continued institutionalization of the residents presently at Pennhurst, Judge Seitz states,"...what is the least restrictive environment for any particular individual is primarily a medical question", a view Congress has specifically rejected.

13. In 1978, Congress created Title VII of the Rehabilitation Act, which establishes comprehensive services for independent living, targeted to "any individual 'whose ability to function independently in his family or community is so limited by the severity of his disability that vocational or comprehensive rehabilitation services...are required to improve significantly...his ability to function independently in his family or community",29 USC § 796(a). In order to be eligible for grants under Title VII, a state must:

demonstrate that the State has studied and considered a wide variety of methods for providing comprehensive services to severely handicapped individuals(such as regional and community centers, halfway houses, and patient-release programs) and that the State will provide, to the maximum extent feasible, meaningful alternatives to institutionalization, 29 USC§796(d)(a)(2).

Thus, the comprehensive services for independent living are meant to supplement the community living arrangements that must currently be available.

During floor discussion on this new Title of the Rehabilitation Act, Senator Stafford, one of its authors, stated:

> The new "comprehensive services for severely handicapped individuals" (the original Senate Bill title) title establishes a new program directed to serve the most severely handicapped individuals. The disabled population to be served by this title...are those individuals who are currently not being served by the vocational rehabilitation programs. These unserved individuals are the severely handicapped and are usually found in our residential institutions. These severely handicapped individuals are going without necessary support services to aid in maximizing their potential. 124 Cong. Rec. S147, 15557 (daily ed. Sept. 20, 1978)

Senator Randolph, the chairman of the Subcommittee on the Handicapped, also remarked:

> At the outset, it must be clear that Section 119 of title I of S.2600 (i.e., Title VII) is targeted on those very severely handicapped persons who need multiple, continuing and probably lifelong services and treatment and who may have little or no vocational potential. It is well to note, however, that there are severely handicapped persons who have much to contribute - if they have access to necessary support services... Giving up too early on these individuals is inconsistent with the Committee's belief that every severely handicapped person is entitled to an opportunity to develop to the greatest extent

The Education for All Handicapped Children Act of 1975 established that every handicapped child, regardless of the type or severity of the handicap, has a right to receive an education. A specific requirement of this law is that each child receive an evaluation of his or her needs and abilities in the form of an individualized education plan, 20 USC §1412(2)(c). Another requirement is that each child should receive an education in the "least restrictive environment" for that child with appropriate accomodations and aids for that child, 20 USC §1412(5).

The legislative history of this act makes it clear that Congress recognized that all children, regardless of the severity of handicap, can benefit from education:

> The...bill has been designed to meet the following purposes...(2)to assure a priority in delivery of services to handicapped children who are not receiving educational services and those handicapped children with the most severe handicaps currently receiving inadequate education. (emphasis added) S.Rep. 94-168, 94th Cong., 1st Sess. at 13, 14, reprinted in (1975) U.S. Code Cong. & Ad. News, 1437, 1438.

> ...an attempt must be made to reach and provide services to children with the most severe handi-

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possible. 124 Cong. Rec. S147, 15548 (daily ed. Sept. 20, 1978)

Congressman Brademas, the chairman of the House Subcommittee on Select Education and a House author of the Bill, pointed out:

> Without question, this section epitomizes what the thrust of this bill is all about - moving away from the stereotype which views handicapped and disabled persons as being unable to exist in a community structure. Here, as in so many other areas, the direction is away from institutional settings and instead moving back into the mainstream. 124 Cong. Rec. H72, 3967 (daily ed. May 16, 1978).

> caps without regard to disability category. S. Conf. Rep. 94-455, 94th Cong., 1st Sess. at 38, reprinted in (1975) U.S. Co-e Cong. & Ad. News, 1491.

Senator Mondale, in articulating a basic concern which prompted the passage of the Act, stated:

> In the past, many children have simply been placed in institutions or segregated in schools and classes with little emphasis on adequate education and training. 121 Cong. Rec. S10983 (June 18, 1975).

When the House of Representatives considered the bill, Congressman Miller, a ranking member of the House Committee on Select Education, stated:

> There is no question that previous emphasis on institutionalization were not only dehumanizing, but neglected the basic precept that these persons have the same rights as other human beings. Most importantly, institutionalization more often than not effectively prevented any chances for a handicapped individual to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities. 121 Cong. Rec. H11350 (July 29, 1975).

Another stated purpose of the Act was to provide educational services to persons whose disabilities were so severe that they had previously not been expected to have the capability to successfully live in society. Congress explicitly repudiated these outdated stereotypes and further made it clear that this Act was intended to promote the capabilities of severely disabled people:

> The long range implications of these statistics are that public agencies and taxpayers will spend billions of dollars over the lifetimes of these individuals to maintain such persons as depen-

> dents and in minimally acceptable lifestyle. With proper education services, many would be able to become productive citizens, contributing to society instead of being forced to remain burdens. Others, through such services, would increase their independence, thus reducing their dependence on society. S.Rep. 94-169 at 9 (1975), U.S. Code Cong. & Ad. News, 1433.

In 1974, Congress enacted the White House Conference on Handicapped Individuals Act, 29 USC §701(1974), appropriating funds for a national conference held in Washington, D.C., in 1977. This conference was attended by people with all types of disabilities from all of the states and territories. One of the concerns that Congress wished to see addressed at this conference was the lack of alternatives and services for the severely disabled:

> The Committee has been distressed to find that services to the severely and multiply handicapped are virtually non-existent. It has discovered in hearings on the Rehabilitation Amendments of 1972 that individuals who are most in need of services have the most severe handicaps and are the last to receive them. S.Rep. 93-319 at 6 (1973).

Again, the legislative history for the White House Conference Act explicitly makes it clear that Congress was fully aware of the potential and capabilities of persons with the most severe disabilities and was also fully cognizant of the fact that those in institutions were least able to realize those capabilities. The reason was and is that resources to live in the community were not sufficiently available:

> All too frequently the adults with handicaps are forgotten because they no longer seem as appealing and therefore elicit the same sympathy as when they were children. The result has been institutional care or heavy dependency on family

> and friends because of a lack of services in the community to allow adults to function as independently as possible. S.Rep. 93-1297 at 51, (1974) U.S. Code Cong. & Ad. News 6401. [14]

II. CONGRESS HAS RECOGNIZED THAT PERSONS WITH DISABILITIES HAVE THE COMPETENCE TO SPEAK FOR THEMSELVES.

Amici have felt it is important to present their views to this Court because they directly represent the people who will be most affected by the outcome of this litigation. While other groups historically have spoken for disabled people - the professionals, the administrators, the parents, the staff - there no longer is a need for them to do so exclusively. With the advent over the past decade of the organizations that have joined this brief, and others, there are now strong, organized voices of disabled people themselves. With the birth of new groups such as People First, representing people who are retarded, there is now a voice of persons who have heretofore been sent off to institutions and, in many instances, forgotten.

Amici's views and experiences on this matter should not be taken lightly. As previously noted,

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14. It is likely that Congress was also aware that historically, the dual policy of establishing institutions and providing community services has not succeeded:

> There is an expansive character to institutions that is not easily curbed - and this in two senses. For one, institutions appear so convenient and functional to the ordinary citizen, so easy a way of getting rid of troublesome or ugly or needy persons, that as long as the institutional option exists, alternatives will never be properly organized and supported. For another, the heads and direct beneficiaries of institutions, be they employees or building contractors, have a way of dominating the budget so as to

Amici have participated in numerous hearings and other forums addressing these issues. In many instances, their experiences and successes have been the driving force behind new programs and concepts allowing people with the most severe disabilities to move back into their own communities with the dignity and back-up services necessary for success.

Amici are the only parties who can represent to this Court that they know from first-hand experiences of the capabilities and strengths of people with disabilities. They do not distinguish heavily between "moderate" and "profound" disabilities because they know from their own lives that the major factor influencing their ability to grow and achieve independence is the environment. They represent countless individuals who were once viewed as "hopeless cases" and who are now managing their own lives, some with more supervision than others.

The Congress has recognized the need for disabled people to speak for themselves and represent their own interests, and it has also further recognized the barriers that disabled people have had to face to do so:

> More than any other minority group, individuals with disabilities have been affected by policy decisions made at every level of government which are developed all too frequently without their continued participation. Until this nation has the foresight to include in all of its planning the need to make all areas of society accessible and usable to individuals with handicaps, they will continue to be excluded and will have little or no opportunity to achieve their basic human right of full participation in life and society. S.Rep. 93-1297 at 56 (1974).

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prevent the growth of quality alternatives. David Rothman, "Can De-Institutionalization Succeed?", New York University Education Quarterly, Fall 1979, p. 16.

In addition, those who purport to speak for disabled people often are limited in their ability to do so to the extent that disabled people themselves can. Often, there are differences of viewpoint, experience, expectation and need that divide the loyalties of professionals, parents or others who have responsibilities in addition to their concerns for the conditions or rights of persons with disabilities.

The Congress recognized this, to the extent that parents are not always fully informed about the capabilities of their disabled children:

> Parents of handicapped children all too frequently are not able to advocate the rights of their children because they have been erroneously led to believe that their children will not be able to lead meaningful lives - however, over the past few years, parents of handicapped children have begun to recognize that their children are being denied services which are guaranteed under the Constitution. S.Rep. 94-168 at 9 (1975) U.S. Code Cong. and Ad. News at 1433.

Indeed, Amici are fully aware that sometimes parents tend to be overprotective of their disabled children, as they can be with children in general, and that they tend to underestimate their capabilities as well. This is fully understandable, since very often a parent will turn first to medical professionals to seek information when he or she learns his child is disabled; those very professionals can be instrumental in implanting negative expectations.

Nevertheless, Congress understood that sometimes parents can be misled into defending positions that are actually defeating to the growth and independence of their children.

When the White House Conference on Handicapped Individuals Act, 29 USC §701, was enacted, Congress made it abundantly clear that it was primarily interested in receiving recommendations from disabled per-

sons regarding solutions to thei problems. It created a National Planning and Advisory Council, specifying that at least ten members should be disabled, §302(b)(1) of the Act. The Council was given authority to "engage such individuals with handicaps and additional personnel as may be necessary", §303(a)(5) of the Act. The Conference was attended by hundreds of disabled persons who addressed a multiplicity of issues, following the Congressional mandate:

> It is essential that recommendations be made to assure that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective... §301(6) of the Act.

Amici believe that by advocating for themselves they can best rebut the commonly held assumption that they are not fully capable of doing so. Congress has consistently confirmed the fact that disabled people themselves hold invaluable expertise regarding the solutions to the obstacles that impede their capabilities. It has relied on their expertise in formulating the legislation designed to remove those obstacles, and it has given disabled people the responsibility to manage their own community programs, 29 USC 796(e).

CONCLUSION

There is no doubt that Congress has thoroughly considered the issue of the most appropriate method of providing care and habilitation to persons who are severely disabled and that it has weighed the evidence for and against the continuation of the policy of institutionalization - and rejected it. The legislative history of all of the major Acts concerning services to disabled persons and the protection of their rights provides the Congressional rationale for that rejection: the recognition that even those persons with the most severe

disabilities are entitled to more than mere custodial care, and that all can benefit from services that are individually tailored and community-based. This Court can do no less. We urge this Court to consider these basic principles when rendering its decision and to affirm the opinion below.

Respectfully submitted,

Steven M. Fleisher
Fleisher and Neckritz
1440 Broadway, Suite 702
Oakland, Ca. 94612
(415) 763-9670

Robert Funk
Deborah Kaplan
Disability Rights Education
Defense Fund
Center for Independent Living
2539 Telegraph Ave.
Berkeley, Ca. 94704
(415) 548-4274

For Amici

APPENDIX A

CASE HISTORIES OF SELECTED INDIVIDUALS REPRESENTED BY AMICI

PEOPLE FIRST INTERNATIONAL:

Bob Borneman: Mr. Borneman is 30 years old; he has been classified severely retarded, both intellectually and adaptively by standards set by the American Association on Mental Deficiency (hereinafter referred to as AAMD). He has resided for twenty years at the Fairview State Hospital in Oregon where he displayed severe behavior problems for which he was treated with drugs. During the first three years of his life, he required extensive medical treatment in hospitals and was abandoned by his family. He was placed in Fairview at the age of four.

In 1975, at the age of 24, he was placed in the community in a group home with other people with retardation. Since then, he has steadily improved to the point that his resident progress record reflects that he has learned nearly all the skills necessary for community living. He holds a semi-competitive job at the Veterans Administration in the microfilm department, and requires no behavior modifying drugs. He is regarded in his group home as a leader and a model and has developed a very pleasant personality. Within a year, he is expected to be able to live in a satellite apartment.

Jim Gleason: Mr. Gleason was born in 1944 and subsequently diagnosed as severely retarded by AAMD standards; he also has a physical disability. He was admitted to Fairview State Hospital in 1947 and resided there for 25 years. While living in the institution, he was not physically active and not expected to ever be able to do much.

He was discharged from the state hospital in 1972 and now resides in a group home. He works at Goodwill Industries and has twice been named worker of the month. He is presently on the waiting list to live in a satellite apartment. Last summer he traveled independently by airplane to a dude ranch in Colorado where he spent his vacation. Since he has left the institution, he has developed many abilities never previously expected; he regularly reads the newspaper and is the source of information about current events and activities for other residents in his group home.

Barbara Kluting: Ms. Kluting was born in 1944 and diagnosed as severely retarded by AAMD standards, with Downs Syndrome. In 1969 she was admitted to Fairview State Hospital and resided there for fourteen years. While there, she displayed the characteristics of a very shy personality and very rarely spoke.

In 1974, she left the institution for a group home. She now works at Garten, a local activities center for persons with retardation specializing in recycling. She has twice been named worker of the month and can now perform all the skills listed on the resident progress record such as self help skills, home skills, personal hygiene, etc. While she was never expected to be able to display such skills and attributes in the institution, she now is no longer shy and talks much more. She has a boyfriend in the community and someday wishes to marry.

Geraldine Miller: Ms. Miller was born in 1941 and later diagnosed as severely retarded by AAMD standards; she also has hypothyroidism, hypoglycemia and a severe speech impediment. She was admitted to Fairview State Hospital in 1953 at the age of 12 and resided there for 23 years. While in the institution, she was very shy and did not get a chance to speak for herself very much due in part to her speech impediment.

In 1976, she was placed in the community in a group home. She works at Goodwill Industries where she has twice received notice as the worker of the month. Since leaving the institution, she has developed a more assertive personality and requests others to take the time to listen to what she has to say even though her speech impediment makes listening somewhat tedious. She has a boyfriend in the group home where she now resides; they plan to marry soon and continue to live there in a double room.

All of the above-described persons are members of People First International.

CENTER FOR INDEPENDENT LIVING

Nancy Rosenbloom: Ms. Rosenbloom is 32 years old. She has severe cerebral palsy and her IQ tests at 60, putting her into the category of mentally retarded. Her speech is mostly unintelligible, except to those with whom she speaks regularly. She requires total personal care to help her bathe, dress and eat. She is increasing her mobility through use of an electric wheelchair operated by mouthstick.

She moved to Berkeley, California, a year ago from a residential program in New York City. A year before moving to Berkeley, she was able to visit there and was attracted by the large number of visibly disabled people in that community who lived in their own apartments and were quite mobile. She immediately decided to move there and did so after a year of planning.

She now resides in her own apartment with a live-in attendant whom she has hired herself, who is paid through funds for Home Support Services from the County of Alameda. As well as assisting her with personal care activities, her attendant also helps her with money management. She is a client of the Center for Independent Living, from which she receives services that assist her to live independently.